Continuum of Care
to Improve the Quality of Life for People Living with HIV and Other Vulnerable Populations

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Juliana Sánchez, Yadira Villaseñor, Roberto León,
Anne Fitzgerald, and Stan Terrell,
IntraHealth International

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IntraHealth International • 6340 Quadrangle Drive, Suite 200 •
Chapel Hill, NC • 27517 • USA • 919.313.9100 •
www.intrahealth.org

INTRODUCTION

Health facilities in the Central American region face significant challenges to delivering quality comprehensive HIV and AIDS care and treatment to people living with HIV (PLHIV) and other key populations at higher risk. The HIV epidemic in Central America is concentrated in certain subgroups, such as sex workers and men who have sex with men. Against the backdrop of widespread homophobia, stigma, and discrimination, hidden HIV epidemics threaten to spread into the general population.

There is an urgent need to integrate community-based support into care and treatment to ensure complementary services and promote HIV prevention through strong referral networks and facility-community partnerships—especially with key populations at higher risk and PLHIV. The USAID|Central America Capacity Project, initiated in October 2009 and funded by the United States Agency for International Development (USAID), was tasked with developing and improving services for PLHIV, people at highest risk of acquiring the infection (including mobile populations), and the general public, through the Continuum of Care (CoC) methodology and development of multi-sector HIV networks in each of the five participating countries (Belize, Costa Rica, El Salvador, Panama and Guatemala). By catalyzing local networks, the CoC methodology optimizes the delivery and quality of HIV care, improves access to services involved in the comprehensive response to HIV, and increases user satisfaction. Although multi-sector HIV networks can take on many functions, their principal role in the CoC context is to facilitate access to services for timely detection of HIV and to incorporate PLHIV into a coherent referral system for improved adherence to treatment and positive health, dignity, and prevention (PHDP).

CONTINUUM OF CARE

The primary purpose of the CoC methodology is to develop systems that provide humane, effective, and high-quality comprehensive and continuous care to PLHIV and their families, with the understanding that HIV is a chronic infection. CoC services are delivered through empowered local multi-sector networks including: the Ministries of Health and Education, Human Rights Ombudsman, community groups, police, faith-based organizations, schools, and PLHIV support groups. A fully developed CoC brings together the five major components of an HIV response.

- Care
- Treatment
- Support
- Counseling and testing
- Prevention.

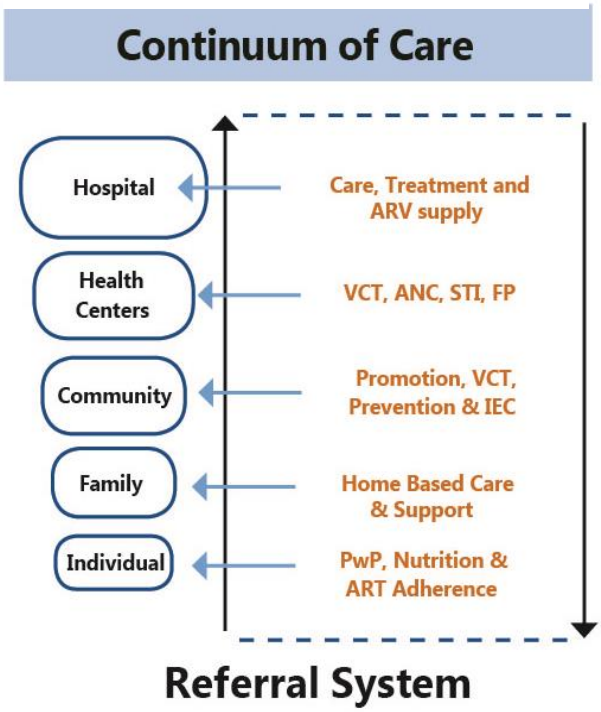
The CoC strategy adapted by IntraHealth, in collaboration with public and civil society partners, is based on a recognized USAID model (Family Health International 2007) and an analysis of experiences and lessons learned in Guatemala. This approach facilitates bidirectional referrals through peer and lay outreach workers, health workers, and community volunteers. IntraHealth also applies the Optimizing for Performance and Quality (OPQ) methodology (IntraHealth Technical Leadership Department 2012) as an organizing framework for quality improvement of CoC implementation.

During the first project year, Capacity collaborated with local counterparts and USAID to assess and select pilot areas and adapt CoC guidelines to the local context. Thereafter, specific elements of the IntraHealth CoC intervention have included training; PHDP; mHealth technology; referral and counter-referral networks; and adherence to performance standards through OPQ.

Training

IntraHealth trains individuals from hospitals, health centers, and nearby community support networks to build capacity and linkages within and outside the formal health sector. Training PLHIV to assist in appropriate levels of service delivery, such as peer support for HIV-positive clients, allows for task-shifting and reduces workloads for hospital staff. Examples of training topics include counseling on antiretroviral therapy (ART) compliance; stigma and discrimination reduction; HIV counseling and testing; gender dimensions of HIV; and PHDP. Training follows Learning for Performance (LFP) guidelines (IntraHealth International 2007) to develop key competencies.

Figure 1: CoC Referral System



Positive Health, Dignity, and Prevention

The PHDP initiative represents a President's Emergency Plan for AIDS Relief (PEPFAR) effort to prevent new HIV infections through interventions with PLHIV. PHDP prevention efforts aim to mitigate the spread of HIV to partners as well as protect the health of infected individuals (PEPFAR 2011). The PHDP initiative is an excellent strategy to further integrate treatment and care with community-based support. IntraHealth supports the following PHDP components to ensure the systematic application of HIV prevention activities for PLHIV:

- Providing prevention recommendations to HIV-positive clients
- Assessing client adherence to antiretrovirals (ARVs) and other medications

- Providing referrals for community-based support and other services.

Because antiretroviral therapy has been found to be an effective prevention intervention, adherence to treatment is a key focus of the CoC effort to both maintain the quality of life of PLHIV and to prevent transmission.

mHealth Technology

To improve community-facility partnerships, IntraHealth has taken advantage of the high prevalence of cell phones in the region to promote text messaging to link PLHIV and community-based groups to health facilities. mHealth can be used to share health information; send prevention messages; follow up with clients; and provide text reminders for when it is time to take ARVs and/or other medications or come for medical appointments. mHealth communications are also a useful means of notifying hospital-community integration team members of meetings, progress made on activities, and other relevant issues, such as bidirectional social networking (health facility to community and vice versa).

Referral and Counter-referral Systems

IntraHealth, in partnership with the various ministries of health (MOH), Social Security Institutes (SSIs), and national HIV/AIDS programs, works with existing hospital-community teams. The teams apply lessons learned to clearly define and promote effective bidirectional referral systems for HIV-positive clients that maximize integration of complementary services. They also work to ensure client satisfaction, promote ARV adherence, and minimize client loss to follow-up. Each local network serves as a nucleus to inform communities about services offered by hospitals and community-based organizations. Each hospital and community organization working in HIV/AIDS receives and posts a list of support entities and services available.

Steps for OPQ Implementation at the Department Level

- Define OPQ standards for CoC networks
- Measure baseline OPQ standards for CoC
- Identify performance gaps
- Develop a plan to improve performance (including a budget)
- Engage in analysis, discussion, revision, and replication in other areas and departments
- Implement and follow up on plans, including limited budget support
- Follow up measurement of performance standards.

Adherence to Performance Standards through OPQ

To ensure the best possible care, treatment, and support for PLHIV, it is critical that all community entities provide services that comply with performance standards for HIV service delivery. IntraHealth provides technical assistance to community organizations and private sector providers to ensure they learn and apply these performance standards and conduct assessments to evaluate health worker performance and productivity. The OPQ approach identifies key areas that need further support and assists participants in making recommendations for resolving these gaps. Identifying factors that motivate health workers to adhere to performance standards is also crucial as it can guide efforts to enhance health worker productivity and build capacity.

One key CoC component is modest financial support (about $3,000–$6,000 per network per year) for the multi-sector HIV networks. The support incentivizes the networks to develop performance gap-closing plans and budgets, carry out advocacy to reduce stigma and discrimination, strengthen services for key at-risk populations and PLHIV, and develop local capacities. (However, it is essential that the level of financial support not be so large as to distract from the need to identify and commit local resources.) For IntraHealth's CoC intervention, the modest financial support has enabled a variety of network activities:

> *"We are facing an epidemic that requires the involvement of all sectors in order to have a positive response…. The work of the CoC networks, with the support of the Capacity Project, has contributed to the national response to HIV in a coordinated way."*
>
> Dr. Ana Isabel Nieto, Coordinator of the National HIV/AIDS Program, El Salvador Ministry of Health, and President of the Central America HIV Regional Coordinator Mechanism, at the First National CoC Networks Forum

- Design and reproduction of educational materials (e.g., banners, t-shirts, pamphlets, flipcharts)
- Purchase of condom demonstration models
- Design and reproduction of performance gap-closing materials (e.g., job aids, guidelines, protocols, norms, strategic plans)
- Refreshments for monthly network meetings and commission meetings to monitor intervention plans
- Travel and per diem for network cross-site visits and network forums.

Using the OPQ methodology, IntraHealth has assisted the local networks in monitoring and evaluating implementation of their performance gap-closing plans prior to authorizing budgets for the following year. IntraHealth has also facilitated South-to-South cooperation through structured site visits to higher functioning networks; forums; and electronic dissemination of key lessons learned and results.

IMPLEMENTATION STEPS

The implementation of the CoC for multi-sector HIV network strategy involves passing through a number of sequential phases and steps (Table 1).

Table 1: Continuum of Care for HIV Phases and Steps

FIRST PHASE		SECOND PHASE		THIRD PHASE				
Presentation & discussion	Situational analysis	Results	Network formation & integration	Baseline measurement	Results	Intervention plan	First follow-up visit	Second measurement

In each country, the Capacity Project's technical and administrative team has supported these CoC implementation steps in a variety of ways:

- Visiting key stakeholders and attending meetings to advocate and negotiate with governmental, nongovernmental, and civil society organizations at the central and local levels
- Performing national and local situational analyses on HIV
- Reviewing results
- Supporting formation of the multi-sector networks
- Completing baseline performance measurements and analyzing results
- Elaborating on the performance gap-closing plans.

Table 2: CoC Networks (2013)

Country	Network Area
Belize	Corozal
	San Ignacio
	Island
	Toledo
	Stan Creek
	Orange Walk
	Belmopán
Costa Rica	Desamparados
	Limon
	Puntarenas
El Salvador	San Vicente
	Sonsonate
	San Rafael
	La Unión
Guatemala	Santa Rosa
	Sur-Occidente
	Petén
	Izabal
	Zacapa
	Huehuetenango
	Quetzaltenango
	Escuintla
	Retalhuleu
Panama	Chiriqui
	Panamá
	Santiago de Veraguas
	Colón

The Capacity Project began with five initial CoC networks. By the end of the third project year, the five networks had completed most of the steps leading up to implementation of their intervention plans (i.e., phase one discussions and situational analysis, phase two network formation and integration, and phase three baseline performance measurement and development of gap-closing plans). In 2011, USAID authorized a significant expansion of activities in all five countries, including a phased expansion to eight more CoC networks in Guatemala and a smaller number of new networks in each of the other countries. By 2013, 27 networks were participating in the CoC intervention across the five countries (Table 2).

It is worth mentioning that the network formation stage is slow and laborious due to the diversity of actors represented; their different areas of expertise and points of view can complicate and prolong the consensus-building process. It can also be challenging to determine who will lead the process and have authority to convene member organizations. In El Salvador and Belize, the regional health authorities assumed this role.

The overall baseline performance scores for the 27 networks ranged from 19% to 62% (average = 35%). Counseling, diagnosis, and ARV adherence were the components with the highest performance scores due to the strengthening of treatment in the HIV clinics. The greatest challenges were management, primary prevention and health promotion, and support services.

The baseline results complemented the information obtained in the situational analyses; both sets of results reflect the fact that government organizations and NGOs are generally not offering these services. Moreover, improving management performance requires standardization of procedures and work instruments used by network member

organizations. Referral and counter-referral systems also require strengthening so that they include other organizations within the CoC networks.

Post-baseline measurement, Capacity provided technical assistance and capacity strengthening to the networks through targeted workshops on network establishment, assertive communication, teamwork, and conflict resolution. By June 2013, when 16 networks underwent their second performance measurements, scores had increased by21 percentage points to an average of 56% (range=31%–71%). (The remaining 14 networks were finalizing their gap-closing plans.) Following the second measurements, the networks focused on gap-closing activities, particularly reducing stigma and discrimination and facilitating treatment adherence through development of referral/counter-referral systems.

> *"The coordinated work of the Sonsonate network lets us provide greater support to our patients and facilitates the adherence to HIV treatment."*
>
> Dr. Rene Arita, ART clinic, Hospital of Sonsonate, El Salvador

Challenges and Solutions

The CoC process of implementing through multisector networks and working with a wide variety of partners is an innovative approach. However, the approach presents particular challenges that require a high level of effort due to the fact that circumstances evolve as the process moves forward. Internally, the Central America Capacity team has used quarterly workshops with field coordinators to regularly evaluate CoC operational activities. Efforts to accumulate experiences through the regularly updated CoC implementation field guide are one way to systematize the process for future implementations.

> *"This training (reduction of stigma and discrimination based on sexual preference, gender, and HIV status) has changed my life.... I will take into practice in my clinic what I learned during the workshop."*
>
> Roxana Castellanos, psychologist, West Petén Health Center, and member of the CoC network of Petén, Guatemala

Network characteristics: Implementation challenges can be related to the composition and interpersonal dynamics of networks. For example, individual members who have a prior relationship may bring interpersonal conflicts into the networks. Workshops on conflict resolution, assertive communication, and team-building are effective remedies in this situation. Another set of challenges involves work with existing networks. Although existing networks are convenient because they bypass the delays associated with starting new groups, some networks may not be oriented toward empowerment and sustainability or may come to CoC activities with unrealistic expectations for project support (especially funding). The Capacity Project encountered a lack of understanding of CoC and resistance to change in some networks. It is, therefore, important to regularly work to align expectations and reinforce the advantages of CoC. This can be accomplished by increasing site visits and creating more opportunities for discussion with networks and individual member organizations, whether by telephone, electronically, or in person. As the Capacity Project experience indicates, these extra

investments of time to sensitize network members about the importance of their active participation pay off. Over time, the local organizations working with the Project have come to display a greater understanding of the networks' role and have shown high interest in participating in the networks as part of a comprehensive solution to the HIV epidemic. Where hospital-community tensions exist, it is important to openly address the situation as part of developing a common perspective and vision for working together to improve the quality of and access to health services.

Commitment: The fact that pre-existing networks are made up of voluntary organizations poses a challenge in that network members may have limited time to dedicate to the CoC process. On occasion, some member organizations displayed low motivation to comply with commitments to implement the CoC strategy, making it difficult to move forward. In response, the Project increased efforts to interact with individual member organizations and used smaller working-group meetings to direct larger implementation efforts.

Monitoring and evaluation: The networks had limited technical capability for conducting the internal monitoring and evaluation needed to facilitate formalization and compliance with activity objectives. To combat this operational challenge, the Capacity Project invested time in identifying key persons and training them on how to document, report, and disseminate network activities. The Project also encouraged networks to incorporate persons with higher skill levels to augment network technical capacity and improve strategic visioning and approaches.

Training: A variety of training challenges can come into play when working with local networks. These include the lack of an agreed-upon approach to reducing stigma and discrimination toward PLHIV and other vulnerable populations, and the need for a training curriculum accessible to audiences that are educationally, experientially, and organizationally heterogeneous. To respond to these challenges, the Capacity Project trainings standardize knowledge and understanding of stigma and discrimination through the development of a competency-based training curriculum using the LFP methodology. The Project also works to maximize network member participation in these training workshops by convincing the heads of the member organizations to take full advantage of the educational opportunities and by implementing systems for convening members for training.

> "*This (assertive communication) training contributes to understanding and evaluating the behavior of working groups in order to designate functions according to their capabilities.*"
> Oscar Muñoz, biosafety coordinator, Western Health Region, Panama

Continuity: The frequent rotation of MOH personnel and resulting delays in decision-making can slow progress and systematization of CoC, especially at the local level. The Project focuses on working with local authorities outside the MOH, and encouraging multi-sector networks to continue scheduled activities despite government delays.

LESSONS LEARNED

Negotiating the formation of multi-sector CoC networks is a complex and prolonged social mobilization process, which requires dialogue and a balance between the visions and interests of multiple stakeholders. Implementation of the CoC strategy requires parallel processes of negotiation with MOH authorities at the central and local levels. However, this dialogue is not limited to government partners. To form a fully participatory network, it is also necessary to allow sufficient time during this initial phase to ensure clear understanding of the CoC strategy and dynamic interrelationship among other sectors. Following this inclusive process builds consensus and harmony, thereby contributing to local empowerment and sustainability.

The process of forming and implementing CoC multi-sector networks is new in many communities. In working with multiple heterogeneous actors, the process requires technical clarity alongside social skills such as team-building, conflict resolution, and strengthening relationships through a systems perspective. Technical assistance providers to the networks must possess negotiation and conflict resolution skills to maintain impartiality and minimize conflicts as they arise. As the process continues, network (and member) dynamics continue to change, which requires documentation and systematization to ensure robust lessons learned and sufficient data for decision-making. Likewise, it is necessary to maintain and disseminate clear information about network activities to keep members fully informed even when they miss meetings.

It is important to incorporate key local decision-makers into the networks to provide necessary support to promote processes and activities. For example, the participation of delegates from local Health Areas may not ensure that Area Directors are informed about network activities. Regular communication with directors and other local leaders is essential to keep them involved and up to date on network progress.

NEXT STEPS FOR THE COC METHODOLOGY

A structured multi-sector community participation approach to addressing HIV at the community level requires intensive accompaniment, patience, flexibility, and communication skills—at least at the outset. The next challenge will be to enable networks to maintain their momentum as Project-sponsored accompaniment and coordination wind down. IntraHealth continues to reinforce actions leading to HIV multi-sector network sustainability, including:

- Promoting national and regional meetings for the exchange of successful experiences and lessons learned
- Facilitating cross-visits between networks to identify and implement activities that support sustainability
- Identifying opportunities and strategies for the institutionalization of HIV multi-sector networks, such as through the National AIDS Commission (NAC)

- Creating virtual spaces to disseminate information on, and tools for, CoC implementation
- Updating the CoC implementation manual based on network experiences to date
- Expanding the geographic areas of intervention within participating countries.

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